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The Project on Death in America

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From its inception in July of 1994 to the present, the Project on Death in America (PDIA) has provided funding for individuals and institutions to address, through research and model systems of care, the barriers to appropriate compassionate care of the dying. The major medical, social and economic impediments include: changes in the trajectory of dying, exemplified by large numbers of patients living for months or years after diagnosis of incurable diseases such as cancer and AIDS; the increasing age of the population; high-technology medical support systems for patients with respiratory and cardiac failure; the greater emphasis on patient autonomy, along with the concerted shift from societal to individual rights; and the limitations in healthcare resources, particularly for patients with chronic medical illness.

The mission of PDIA is to understand and transform the culture and experience of dying through initiatives in research and scholarship, the arts and humanities, through innovations in provision of care, through public and professional education and through public policy [www.soros.org/death]. PDIA is a programme of the Open Society Institute, a non-profit foundation created by George Soros to support the development of open societies worldwide [www.soros.org]. Mr Soros established the project because of his own experiences with the death of his parents. PDIA has committed $35 million over the past 7 years and another $15 million will be granted in the next 2 years to help build capacity and institutionalize palliative care.

PDIA has created and funded a Faculty Scholars Program, a Social Work Leaders Program and a nursing leadership summit and consortium. It has also funded a broadly based grants programme, and through a series of special initiatives has attempted to focus attention on the needs of vulnerable populations—with special attention to children, prisoners, minorities and the elderly.

FACULTY SCHOLARS PROGRAM

The Faculty Scholars Program was developed to create a cohort of clinicians, researchers and educators committed to working in the area of palliative care. It promotes the visibility and prestige of these clinicians in end-of-life care and enhances their effectiveness as academic leaders, role models and mentors. To date, PDIA has supported 78 faculty scholars through 67 awards, representing 50 medical schools (including 4 in Canada) and 3 schools of nursing.

These physician and nurse faculty scholars are committed to institutionalizing change in their clinical practice, education and research environment, working towards this goal in disciplines including medical ethics, medical education, economics, geriatrics, psychiatry, critical care, neurology, paediatrics, paediatric oncology, general medicine and nursing. Since most Americans still die in institutions—hospitals or nursing homes—there is a critical need for people in these institutions who can foster beneficial changes in the care of the dying. Participants are helped in gaining the knowledge and skills to develop innovative programmes in clinical care, research, education and advocacy and to become leaders in their institutions and nationally.

The PDIA Faculty Scholars Program has developed an intellectually vibrant, mutually supportive and cross-fertilizing network of colleagues. In the first three years the programme attracted applications from a geographically diverse pool of applicants and produced an influential group of alumni who have obtained additional grant funding and continue to extend their work on end-of-life care issues. Importantly, these faculty scholars are now mentoring a second generation of scholars.

SOCIAL WORK LEADERSHIP DEVELOPMENT AWARD PROGRAM

PDIA established a Social Work Leadership Development Awards Program to ensure that social workers can provide essential psychosocial support to terminally ill patients and their families through counselling, case management and advocacy services. These awards promote innovative research and training projects that reflect collaboration between schools of social work and practice sites. To date, 23 social workers have been selected.

NURSING INITIATIVES

PDIA has funded two major initiatives by the nursing profession in palliative care. The first was the Nursing Leadership Consortium on End-of-Life Care. The Consortium brought together key national nursing organizations

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Box 1 **Seven priority areas for grant funding of PDIA**

1. The epidemiology, ethnography and history of dying and bereavement in the USA
2. The physical, emotional, spiritual and existential components in dying and bereavement
3. The contribution of the arts and humanities
4. The design, implementation, evaluation and dissemination of new service-delivery models for dying persons and their network of family and friends
5. The design, implementation, evaluation and dissemination of educational programmes for the public about death and dying
6. The design, implementation, evaluation and dissemination of educational programmes for the healthcare professions
7. The shaping of governmental and institutional policy

to develop a coordinated and collaborative nursing agenda within the areas of practice, policy, research and education. The second was the Nursing Leadership Institute on End-of-Life Care. Based at Johns Hopkins University, the Institute's role is to advance the profession's agenda to improve end-of-life care by increasing the leadership capacity of nurses. The project builds on the priorities developed by the Consortium and the commitment and strength of various nursing specialty organizations that represent over 600 000 nurses. A major implementation of the Consortium's agenda is the creation of a centralized Internet resource site run by Sigma Theta Tau International [www.palliativecarenursing.net].

BROAD-BASED GRANTS PROGRAMME

The PDIA grants programme initially defined seven priority areas for funding, distributed through a four-part cycle over the first two years of the project (see Box 1). This process served to demonstrate the level of interest, expertise, and need in these areas. PDIA received over 1500 letters of intent and eventually funded 94 projects. These projects ranged in funding from $5000 to $300 000, all addressing important issues related to the care of the dying. Examples of funded projects include: support for bridging programmes for families in which patients dying from AIDS help to create fostercare alternatives for their children; underwriting the Missoula (Montana) Community Project to study death and dying in a community setting; supporting a novel home care programme for homeless substance abusers dying of AIDS and cancer in Washington DC; a major grant to the United Hospital Fund in New York City to develop a programme to establish palliative care programmes in twelve New York City hospitals; and a series of special reports. One of these, the Institute of Medicine report *Approaching Death*[1], outlines barriers to excellent end-of-life care and makes a series of recommendations to governmental, non-governmental, educational and public groups to encourage the development of policies and procedures to address the needs of dying patients. PDIA also supported the Alliance for Aging Research to publish *Seven Deadly Myths*[2], a report describing the myths surrounding the high cost of care for the elderly, and a second report entitled *One Final Gift*[3], focusing attention on the particular needs of women and developing policies to improve the care of the dying. PDIA is currently helping initiatives to advance paediatric palliative care through support of a new Institute of Medicine study that focuses specifically on the special needs of children at the end of life.

Another component of the grants programme has been to emphasize the important role of communities in addressing the need for bereavement services. PDIA, through its Community Support for Grief and Bereavement Initiative, is funding innovative strategies for making individual and community bereavement services available and for developing local educational bereavement programmes. As part of this initiative, PDIA has committed funds to the Center for the Advancement of Health to develop a major effort to build an academic field in grief and bereavement through a consensus-building project that will set an agenda for the necessary research and clinical care systems needed in the US.

To emphasize the contributions of the arts and humanities in transforming the culture of death, PDIA encouraged persons from the literary, visual and performing arts to identify, create and convey meaning in facing disability and death, and to invoke and deepen our understanding of the diverse myths and metaphors that shape the experience of suffering in dying and bereavement. Through the Arts and Humanities Initiative, PDIA funded a total of 19 proposals. Included in these projects are Eugene Richards' *Auburn: a Video Documentary*, which elucidates and personalizes 'ageing' through the lives of the 'oldest old' (people aged 80–100) in Auburn, Nebraska[4]; Lisa J Schnell's autobiographical book *Learning How to Tell*, recounting her intellectual and spiritual journey back to life after the loss of her youngest daughter; and an exploration of contemporary experiences of dying in Alan Shapiro's book of poems *The Dead Alive and Busy*[5].

PDIA grants reflect the seven priority areas identified at the beginning of the project; however, the project continues to refine these priorities.

SPECIAL INITIATIVES

One of the underlying principles of all of the efforts of the Project on Death in America is to focus attention on the needs of vulnerable populations and to better understand the obstacles they encounter in pursuit of appropriate end-of-life care.

Increasing numbers of prisoners are dying without access to compassionate release. PDIA—together with another Open Society Institute programme, Crime, Community and Culture—sponsored two national meetings on dying in prisons and jails, and developed a short documentary on the development of a hospice programme in Angola Prison[6]. As a result of these efforts, there are a series of ongoing initiatives to advance the care of dying prisoners and make available to them appropriate pain and palliative care measures through the development of guidelines, educational initiatives for prison healthcare professionals, and policy changes.

Through its African-American initiative, PDIA has identified specific barriers to the provision of end-of-life care for minorities[7]. PDIA is supporting the development of a network of collaborative organizations to identify the barriers and find ways to improve care for African Americans.

Economic policy initiatives

PDIA is working with economists and healthcare policy experts to better understand how economic disincentives prevent appropriate compassionate care at the end of life. PDIA has funded several economic projects as well as supporting Americans for Better Care of the Dying (ABCD), a grassroots organization created to address patients' economic and policy concerns. Joanne Lynn, the country's leading expert in policy and financing issues on end-of-life care, leads this initiative. She and her staff have developed a series of policy initiatives including payment for pain medications, appropriate billing codes for palliative care, and a 'Medicaring' policy. Lynn's studies indicate that Medicare is inadequately designed to meet the chronic care needs of seriously ill and old patients for symptom control, caregiver assistance and home care. The elderly, often having outlived their family members and spouses, have limited resources and their complex ills commonly include cognitive failure. If the Medicare system is to be reformed, this must be done soon to meet the needs of the expected three-fold increase in the aged population in the next ten years. Care for the elderly is now on the national agenda.

Legal policy initiatives

As part of its legal initiative, PDIA invited a group of litigators representing the broad spectrum of right-to-life, right-to-die, disability, and civil rights advocacy groups to an exploratory meeting to assess the desirability and possibility for litigation to address State and federal legal barriers to adequate care at the end of life. These experts clearly identified the lack of a resource centre with expertise in all aspects of end-of-life care. To begin to fill this gap, PDIA has funded a palliative care lawyer at the Bazelon Center for Mental Health Law in Washington DC. Mary Baluss, JD, is now working with our PDIA network of scholars and grantees to identify potential litigation cases and help to provide background information and legal expertise to physicians and other healthcare professionals who are struggling to defend themselves on issues of appropriate pain management, the withholding or withdrawal of care, end-of-life decision making and comfort care practices.

Palliative care initiatives in Eastern Europe

PDIA is currently working with the Soros Foundations in Eastern Europe both to identify barriers to appropriate care at the end of life and to develop strategies and model programmes for hospice and palliative care in the region. For this purpose PDIA, in collaboration with the Public Health Network Program of the Open Society Institute, has committed $500 000 a year for the next three years to fund healthcare professionals, associations and organizations working in the countries of Eastern Europe. The Eastern European Palliative Care Initiative has targeted seven programme areas for funding—namely, resource/training centres in palliative care; regional policymaker meetings to bring together health ministers; meetings of drug regulators and economists from the region to discuss healthcare policy and drug regulation and reform; national and regional professional education programmes to provide local and regional educational opportunities for physicians, nurses and social workers; palliative care scholarships for identified end-of-life care experts to spend time training at centres of excellence; travel grants for healthcare professionals to attend international conferences; and grants to translate existing palliative care educational materials into local languages. 200 applications were received for the first award cycle with 53 grants awarded. The second grant award cycle will be announced in late 2001.

EXPANDING PHILANTHROPIC SUPPORT

To encourage broader philanthropic funding in this area, PDIA joined with a series of foundations to create Grantmakers Concerned with Care at the End of Life [www.gccel.org]. This initiative is working to expand funding coalitions in end-of-life care and serves as a resource to foundations about opportunities for supporting end-of-life care.

PDIA serves as a model programme for non-governmental philanthropic organizations that can help to create momentum for change in transforming the culture of death. There is a need for international groups to address these important topics on the care of the dying and to see such issues as integral to all programmes caring for the elderly and for patients with AIDS, cancer, and chronic disease in general. From numerous public surveys, nationally and internationally, there is evidence to suggest that the public have complex and at times contradictory, attitudes to death and dying. They consider their own death with a mixture of dread and procrastination. They fear overuse of medical technology, want personal control, and are afraid of being a burden. These attitudes can only be addressed by developing broad-based programmes for improving communication and decision-making at the end of life, by changing the culture of healthcare institutions and by changing attitudes to death.

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